A Question of Adherence: An Anthropological Perspective

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Culture Shapes Health & Disease

- **Epidemiology (social practices, risk/triggering factors)**
- **Symptom content, form, constellation**
- **Illness identification, definition, and meaning**
- **Social-emotional response, support, stigma**
- **Gender and ethnic variation / similarity**
- **Utilization of health care sectors**
- **Use and experience of treatments, medications**
- **Prevention, course and outcome**

Conceptualizing Culture

"The true locus of culture is in the shared symbols and meanings that people create and recreate in the process social interaction."

Edward Sapir, *"Culture, Genuine and Spurious"* (1924) and *"The Symbol"* (1933), *The Psychology of Culture* (J. Irvine, Ed., 1994:224)

Conceptualizing Culture

- **Process orienting fundamental human capacities:**
  - **Self**
  - **Cognition**
  - **Emotion**
  - **Social Attachment**
  - **Healing**
- **Culture shapes human being:**
  - **Experience**
  - **Behavior**
  - **Meaning**

(J.H. Jenkins & R.J. Barrett. 2004. *Schizophrenia, Culture, and Subjectivity: The Edge of Experience*, Cambridge University Press)

Cultural Challenges for “Adherence”

- **Perspective**
  - **Patients**
  - **Providers**
  - **Families**

- **Explanatory Models**
  - **Conceptions**
  - **Causes**
  - **Treatment**

Problem of adherence: social hierarchies

- **Health care replacement for 'compliance:'**
  - patients not passive
  - medical authority of "Thou shalt . . ."
- **Anthropological study of social hierarchies:**
  - cooperation & challenge, acquiescence & resistance
  - interactive dynamics of dominance & submission changeable over time

Problem of adherence: involves cultural expectations & values

- **Values surrounding respect/ honor /violation in healthcare encounters**

- **Invocation of cultural expectations and moral "goodness"**
  - "you're not taking care of yourself"
  - "you're not listening to me"

- **Divergent understandings of core cultural health assumptions:**
  - "choice" / "possibility"
  - "rational decision-making"
  - "personal responsibility"
  - "risk" and "prevention"

Problem of adherence: Not a one-way street

Parties assess how *each other engages or 'adheres'* to:

- **respected communication**
- **perspectives / explanatory models**
- **values, core cultural health assumptions**

Adherence: Example of Medication Model for Barriers to Treatment

- Poor provider-patient communication
  - Patient has poor understanding of disease
  - Patient has poor understanding of benefits & risks of treatment
  - Patient has poor understanding of proper use of medication
  - Physician prescribes overly complex regimen
- Patient's interaction with health care system
  - Poor access/missed appointments
  - Poor treatment by clinic staff
  - Poor access to medications
  - Switching formulary / high medication costs
- Physician's interaction with health care system
  - Poor knowledge of drug costs
  - Poor knowledge of insurance coverage
  - Low level of job satisfaction

From Adherence to Engagement

- Extend thinking about placebo -- as emotional response/ activation -- greater provider attention enhances treatment outcome
- If extent of placebo response is enhanced by physician contact, would this not similarly apply for problems of "adherence?"
- Improving 'adherence' may hinge on role of practitioner involvement to enhance treatment efficacy
- Patients more 'adherent' when receive better attention from health care providers?
- Is response to treatment enhanced by better provider attention in a way that is additive to regularly adhering to medication regimens?

Leads to Notion of Engagement as Central to Effective Adherence

- What do I define 'engagement?'
  - not just a matter of behavior (prescribing, taking/not taking meds)
  - shared hope, listening, basic understanding of treatment & costs/ impacts
  - knowledge of what treatment 'means' (as for placebo conceived as "meaning response," Moerman 2002)
  - knowledge of how treatment works in everyday social milieu

- Engagement -- to be effective -- must be two-way street
  - cannot get patients involved without practitioners, and vice versa
  - 'adherence' not an 'on/off' switch

- Adherence conceived as Engagement makes providers' jobs:
  - ***more*** complex, not less;
  - *more* long-term vs. short-term, and
  - critically, *more* effective than less, with greater satisfaction

Improvement and Recovery from Treated Schizophrenia

- “We see that recovery is an important and fundamental phenomenon. Although the phenomenon will not fit neatly into natural scientific paradigms, those of us who have been disabled know recovery is real because we have lived it” (Deegan 1988).

- "With modern advances in drug therapy and psychosocial care, almost half the individuals initially developing schizophrenia can expect a full and lasting recovery. Of the remainder, only about one-fifth continue to face serious limitations in their day-to-day activities" (WHO 2001:33).

- “We envision a future when everyone with a mental illness will recover” (U.S. Presidential Commission on Mental Health 2003).

Subjective Experience and Culture of Recovery with Atypical Antipsycotics (SEACORA)

NIMH Grant MH-60232

Research Questions:

- What is the subjective experience of taking "second-generation" antipsychotics for persons with schizophrenia-related disorders?
- What are the personal and cultural meanings of taking these medications?
- What is the subjective sense of the effect of these drugs on illness exacerbation, improvement, & recovery?
- Does improvement affect community integration and social stigma?

Methods for Study of Medications

Perspective of patients: illness experience, management, and improvement/deterioration at stake in taking or utilizing meds

Qualitative data on medication use may be revealing for adherence research by:

(1) interpreting & complementing quantitative, scalar-based data

(2) fleshing out medication-related behavior

(3) identifying additional factors and processes to elaborate

SEACORA Study (N=90)

- Ethnographic interviews, naturalistic observation of clinical, public and home settings of a U.S. urban community, using anthropological techniques and standardized instruments for research diagnosis (DSM-IV,) and symptom severity

- 'Treatment-refractory:' 20 yrs ill (mean)

- Switched to atypical / 2nd generation antipsychotics

Common motivations for regularly taking medications

- **Use of medications gives symptom control**
- **Avoid rehospitalization**
- **Fear of symptom relapse or exacerbation**

Jenkins, J.H., Carpenter-Song, E. The New Paradigm of Recovery from Schizophrenia: Cultural Conundrums of Improvement without Cure. ***Culture, Medicine, and Psychiatry*** 29(4):379-413.

Do participants regularly take medications as prescribed?

While not an adherence study, spontaneously reported:

- **23.4%** of participants reported never missing a dose
- **76.6%** reported occasionally missing a dose

- **91.4%** of participants said they "regularly" took their medications as prescribed (coded as "always" took meds, took meds "everyday," "regularly" or as an "automatic" routine, or never or only "accidentally" miss a dose)

What did regular adherence involve?

- Previous severe and extended illness experience
- Improvement subjectively experienced by majority; understood as *gradual* process*
- Taking medication regularly despite residual symptoms & troubling side effects (e.g., weight gain, sexual impairment)
- Culturally-specific meanings of medication use
- Active struggle along with daily medication
- Taking medication despite social & existential dilemmas

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* Objectively observed by low BPRS symptom levels (Jenkins, Strauss, Carpenter et al. 2005. Subjective experience of recovery from schizophrenia-related disorders and atypical antipsychotics, ***International J Soc Psychiatry*** 51(3):211-227)

Additional source: Jenkins, J.H., Carpenter-Song, E. The New Paradigm of Recovery from Schizophrenia: Cultural Conundrums of Improvement without Cure. ***Culture, Medicine, and Psychiatry*** 29(4):379-413.

Sense of Improvement as Gradual Yet Steady

- improvement described as incremental process
- gradual yet subjectively discernable
  - "The nice thing about it [meds] is that you do feel yourself getting better little by little, day by day, but you can feel it."
- process perceived as not necessarily linear, periodic set-backs followed by rebounds

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Paying the Price of Adherence: Rank-Order of Most Troubling Side Effect

	Overall (N= 88)*	Men (N=48)	Women (N=40)
Weight Gain	18.2**	**14.6**	**22.5**
Drooling †	17.0	14.6	20.0
Tired/drowsy	17.0	16.7	17.5
Tremor/stiff	10.2	10.4	10.0
Sex. Dysfun.	5.7	**10.4**	**0.0**
Anxiety/fear	5.7	8.3	2.5
Gastrointest.	3.4	4.2	2.5
Blood draws	3.4	2.1	5.0
None* **	**19.3**	18.8	20.0

***N < 90 due to non-response**

**** Reported as percentages**

† Drooling reported significantly more for clozapine patients (Fisher's exact, p<.001)

***** Response of "none" sometimes accompanied by "relative to older meds"**

May not equal 100% due to rounding

(Jenkins, Strauss, Carpenter et al. 2005. Subjective experience of recovery from schizophrenia-related disorders and atypical antipsychotics, *International J Soc Psychiatry* 51(3):211-227)

Culture Affects Experience of Effects and the Meaning of Taking Medication

- somatic modes of attention, or culturally distinctive ways of paying attention to the body:
  - "I can feel clozaril working in my arms and face. I feel safer, I can feel it working."
- metaphorical representations, how medications "work"
  - "(medication) is a mental dam"
  - "(being psychotic is) Like being a passenger in a car with no driver going at top speed, weaving in and out of traffic. . . medication is like having a driver."

Meanings of What Medication Does Does

- “Protects”
- “Keeps”
- “Clears”
- “Controls”
- “Helps”
- “Attacks”
- “Mellows”

- “Organizes”
- “Numbs”
- “Regulates”
- “Slows”
- “Stabilizes”
- “Blocks”
- “Releases”

Meaning of Medication "Action"

These simple verbs, often linked to metaphors in the narratives, indicate the complexity and variation of medication experience

Medication Attitudes & Practices

Fear of addiction:

- **"I need medicine, but I don't want to be addicted to it either."**

Side-effects:

- **"Zyprexa makes me gain weight. So that's a big reason I don't like to take it."**

Drug "Holidays:"

- **"Once a week. . . I'll go without taking my morning medication. I'll just take my bedtime medication. . . I feel over drugged, I feel a need to clear my system of some of the toxic effects of the drug."**

Medication Attitudes & Practices

Social influences:

- **"My brother, Bill…he said to hell with the medicine."**

Fear of chronicity:

- **"And I'm wondering, will I have to be on medicine all my life, or will I not have to be on medicine all my life?"**

Paradox of "improvement/recovery without cure"

- **"It seems like the longer I struggle with it, the easier it gets. . . . But I'm wondering if maybe someday they'll find a cure for schizophrenia."**

Desire and confusion surrounding a "cure" for schizophrenia

"I'd like to be healthy and I'd like my illness to be in remission. And I'd like to be cured of my illness if it's possible, and, uh, if, to the best of my knowledge, is that there's not a cure for schizophrenia. But, like I said, it depends on the doctor's philosophy, too. (Uh hm.) Some say there are cures for all illnesses, some say there aren't. And some say you can put illnesses in remission, and cure them, so I don't know."

Medication Attitudes & Practices

"**Catch-22s" and ambivalence**

- **"Crazy or fat? I choose fat."**
- **"I'm real scared to be without them. I feel handicapped by the fact that I'm going to be miserable without them…I feel handicapped that I have to take them… I'm trapped if I don't take them."**

Cultural interpretations of biochemistry:

"…I guess it works with the juices in the brain, the chemicals in your brain…Maybe it regulates it. . .or I might be lacking endorphins or something like that."

Medication Logistical Worries

- “They’re expensive. I have to stay on social security to get them. The worst thing is the price. I’m worried I’ll be a senior citizen and won’t be able to afford the drugs. I’ll be up a creek.”

Active Personal Engagement

- “I think it needs to be more than just medication. When I hear the voices, there's a combat in my head. There's a struggle. I have to fight 'em. And if I just go with the medicine, it doesn't work. It takes actually distracting myself and making the effort, cooking, watching TV, walking, going to church. . .”

- “I can control the way I think. Like, if I have a sick thought I'll just allow myself to recognize it as a sick thought.”

Social & cultural dilemmas for engagement: No magic bullet, No rubber bracelet

- **'Recovery' without 'cure'**
- **Social stigma *despite* improvement**
- **Psychopharmacology without psychotherapy**

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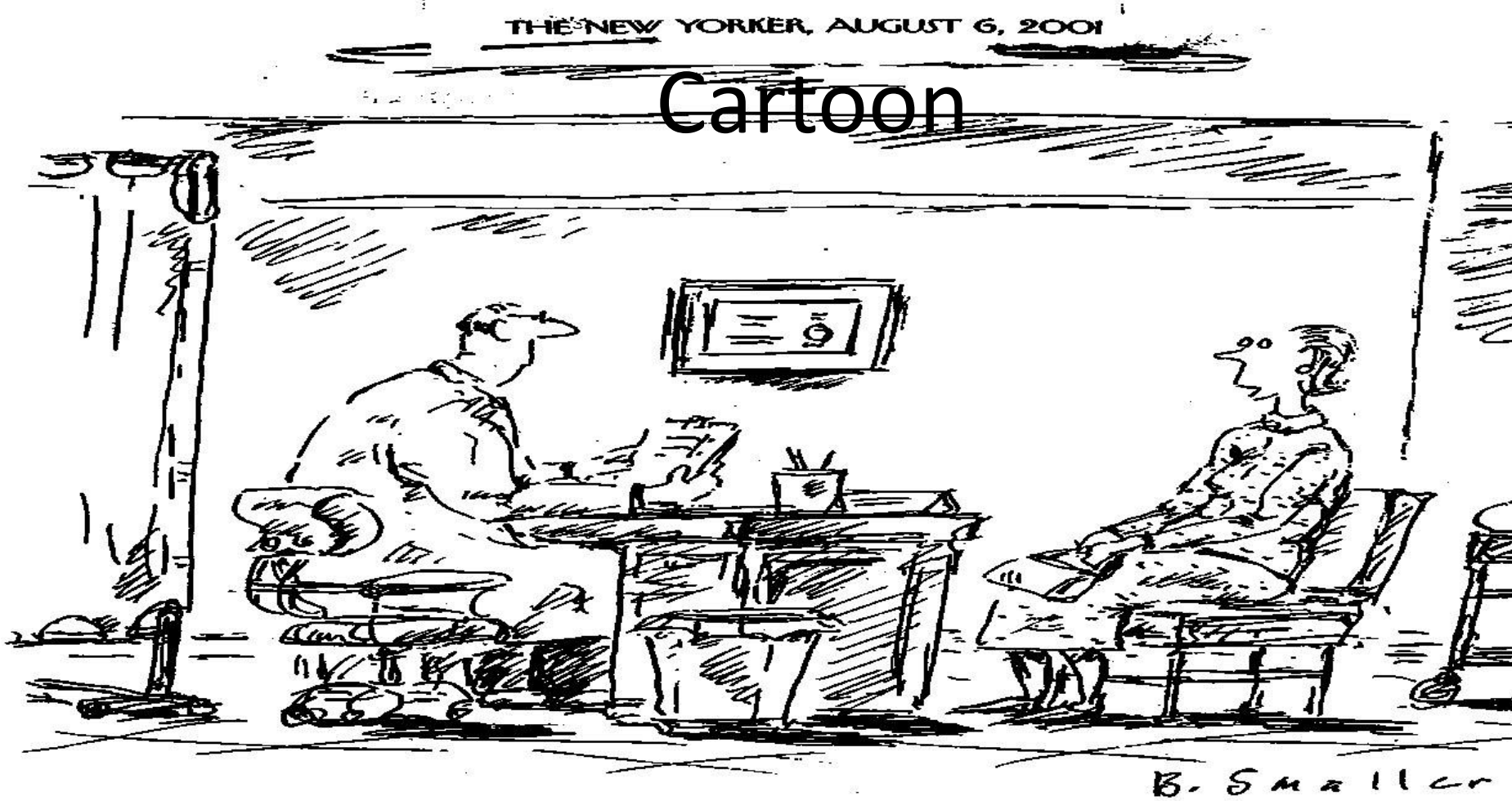
Jenkins, Janis H. and Elizabeth Carpenter-Song. 2009. "Awareness of Stigma among Persons with Schizophrenia: Marking the Contexts of Lived Experience." ***J Nervous and Mental Disease*** 197(7):520-259.

Cartoon



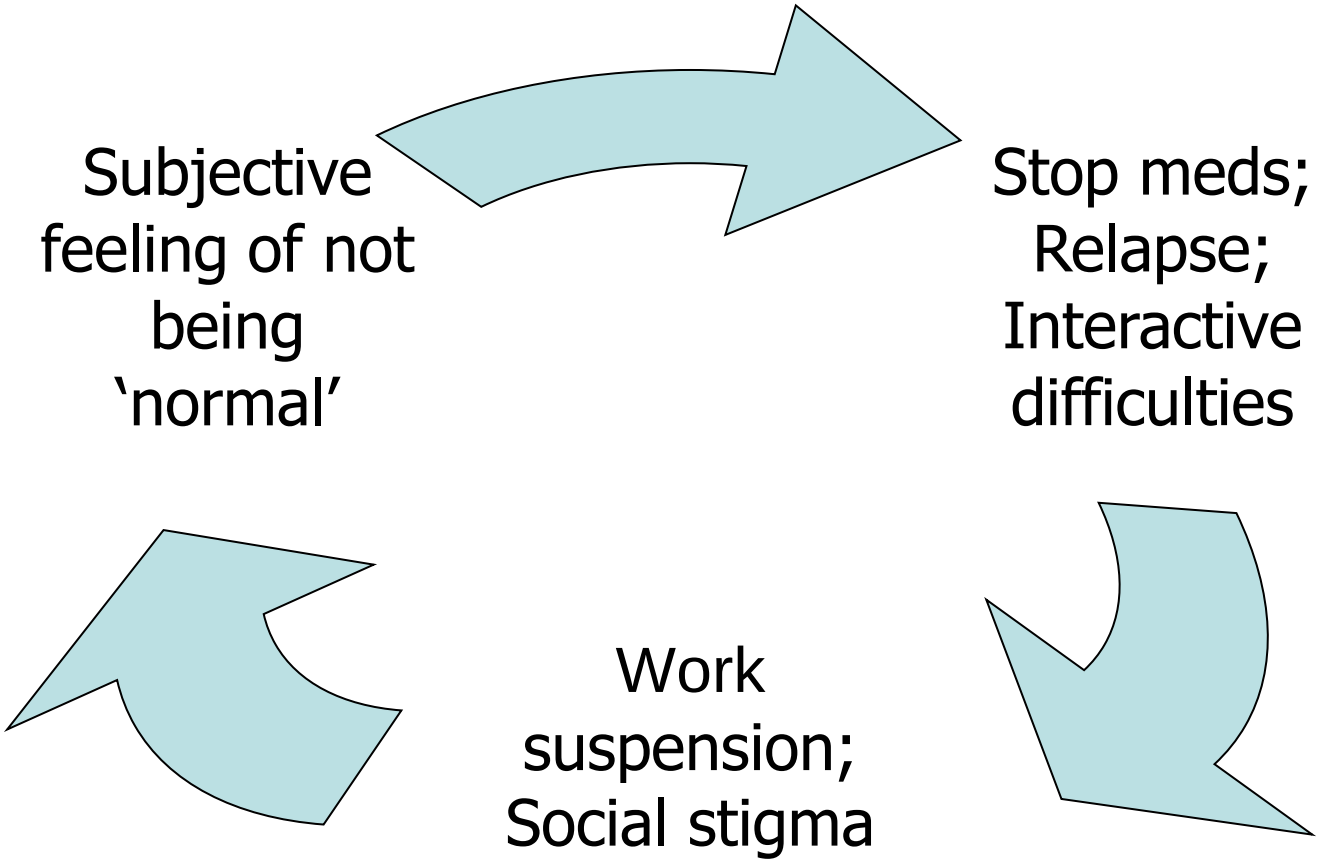
"I think the dosage needs adjusting. I'm not nearly as happy as the people in the ads."

Strategies for Self-Protection and Resistance to Stigma

- Concealing diagnosis or medications
- Avoiding others
- Attempts to “pass” for normal
- De-emphasizing illness
- Relativizing the illness
- Educating others about mental illness
- Socializing with others with mental illness or those who sympathize
- Confrontation and opposition
- Humor and joking
- Reproduction of stigma

Jenkins, Janis H. and Elizabeth Carpenter-Song. 2008. “Stigma Despite Recovery: Strategies for Living in the Aftermath of Psychosis.” *Medical Anthropology Quarterly* 22(4):22(4):381-409.

Fear of Stigma in the Work Setting



Relation Among Factors Perceived by Patients as Critical to Improvement

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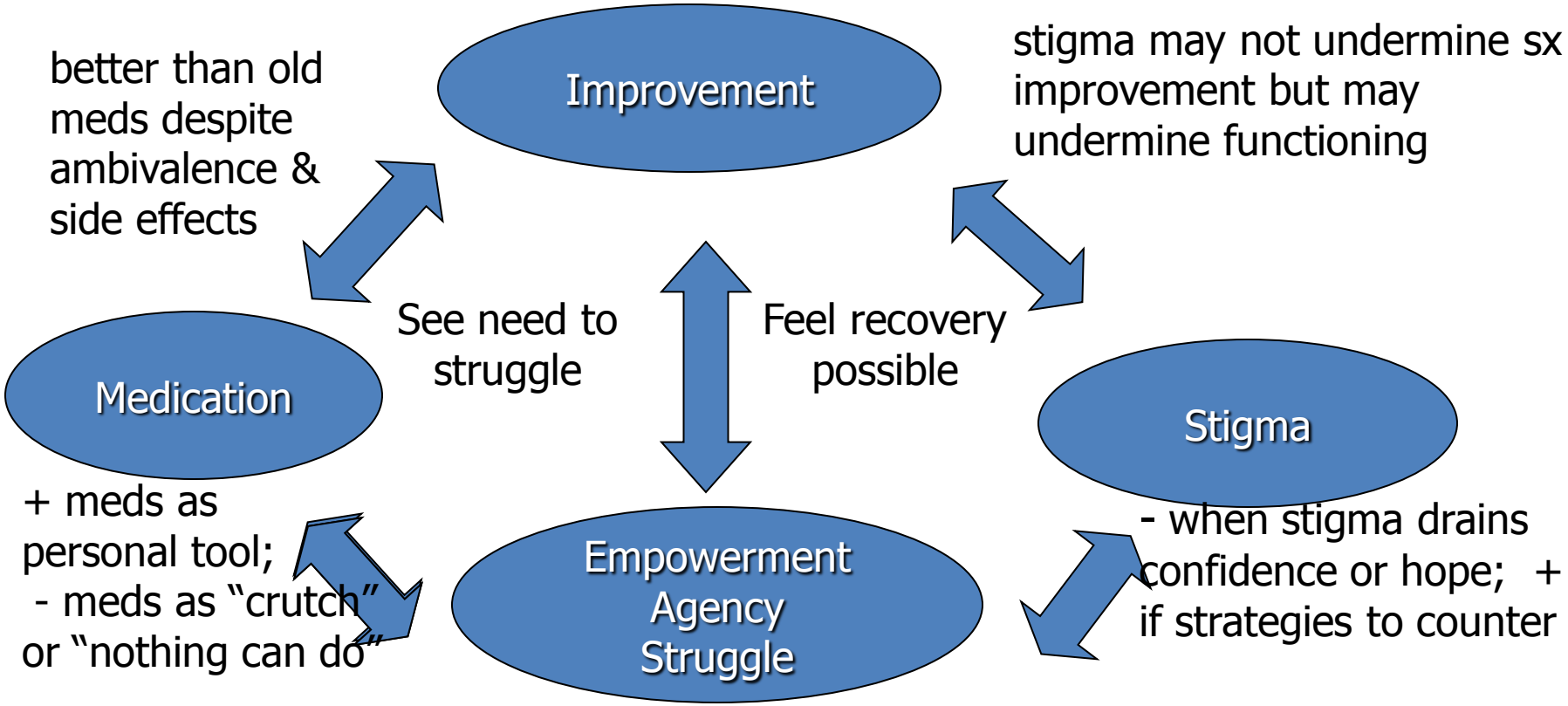

Person-Illness-Meds Experience

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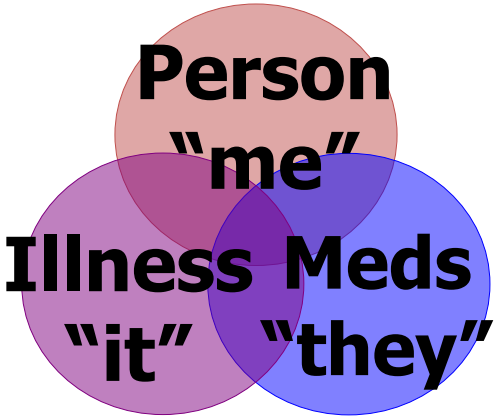
Pattern I

Interaction among person/illness/medication creates possibility for agency, facilitated by medication but localized in the person:

personal power through taking meds



Pattern II

Interaction among person/illness/medication negates possibility for agency, preempted by medication but is outside of personal control:

taking meds renders personal power irrelevant

Recommendations

- **Terminology of diagnosis and treatment conveyed through negotiation of clinical-cultural valences**
- **I suggest problem of** adherence **be conceived as problem of shared *engagement**
- **Fostering realistically-based shared hope, listening, and understanding of treatment and costs (biological, social, cultural, economic)**

***(Jenkins *under review*, and 2004 *Schizophrenia, Culture, and Subjectivity: The Edge of Experience*, Cambridge University Press)**